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Published in:
European Journal of Public Health

DOI:
10.1093/eurpub/ckr088

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European Journal of Public Health, Vol. 22, No. 4, 529–533

doi:10.1093/eurpub/ckr088 Advance Access published on 12 July 2011

Children's opinions about organ donation: a first step to assent?

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Background: Parents have to decide about organ donation after the death of their child. Although most parents probably would like to respect their child's intentions, parents often are not aware of their child's wishes. This requires insight into children's opinions about donation. **Methods:** An internet survey that investigated whether Dutch children in the age range of 12 through 15 years had heard about organ donation, what their opinions were on donation and whether the topic had been discussed at home. Questionnaire response rate 38%. **Results:** Around 99% of 2016 responders had heard about organ donation and about the possibility of becoming a donor, 75% preferred to decide for themselves about donation, 43% had discussed organ donation more than once at home, 66% were willing to donate. The willingness to donate was positively associated with age and socio-economic status. **Conclusion:** This survey indicates that these children at 12 through 15 years of age are capable and willing to think about organ donation. Thought should be given about how to raise awareness and how to enable parents and children to develop some sort of health literacy concerning the concept of organ donation. Children and their parents should be given adequate opportunities to receive appropriate information, suited to their psychological and moral developmental status.

Introduction

Being asked as a parent to decide about organ donation, after having just been informed of the unexpected death of one's child, is probably one of the gravest and most difficult moments in life. This decision undoubtedly has a drastic impact on how parents cope with their loss and, consequently, on their long-term quality of life.[1] Since so much is at stake, and given the fact that most parents have not thought about donation before,[2] health professionals need to guide the parents through the difficult process of making this decision. According to Randhawa,[2] the child's opinion about organ donation is one of the arguments that parents should be able to use. In such cases the parents' informed consent would be able to include or build upon what could be regarded as the child's 'posthumous assent'.

Assent means a child's agreement to medical procedures where he or she is not legally authorized or has insufficient understanding to be competent to give full consent.[3] Many physicians will recognize Randhawa's[2] plea in their own clinical work, especially when it concerns children reaching puberty. Although empirical figures are lacking, parents of children often refer to their child's 'attitude of generosity' when they are considering donation, and sometimes they even refer to the child's opinion about donation itself. The concept of posthumous and therefore delegated assent raises questions about a number of pre-conditions that have to be met in order to allow the parents the possibility of following the wishes of their child. These pre-conditions should, in our opinion, at least comprise the child's maturity and health literacy as well as the parents' accessibility to the child's opinion.

Maturity means that a child is cognitively and emotionally developed enough to give assent. When discussing the ability of children and adolescents to make difficult decisions, especially ethical or moral decisions, one is most often referred to Kohlberg's work on developmental psychology.[4] Although no research has been done on the relationship between maturity and the ability to make moral decisions on organ donation, there is empirical evidence that from the age of 9 years children are cognitively and emotionally capable of providing assent under normal conditions.[5] Health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.[6] Health literacy partially overlaps maturity but adds the precondition that a child should have a certain amount of information and knowledge about organ donation to form their own opinion. Accessibility to the child's opinion means that parents must have had access to the opinion of their child in order to be able to take this into account posthumously.

We conducted a literature search on organ donation in paediatrics in the databases: Embase, Amed, Eric, PsycINFO, Google Scholar and Medline. We found no specific literature and discovered no specific empirical data on donation for any of these conditions; studies so far have only focused on the opinions of older high school students, older adolescents and young adults.[7,8] Studies on health literacy or on the access of parents to their child's opinion at younger ages as far as donation is concerned are completely lacking. To address this gap, we conducted a survey on the health literacy of children (from 12 to 15 years) regarding donation. We hypothesized that these children would be mature enough to be able to think about the topic. Specifically, this survey investigated whether children had heard about organ donation, what their opinions were on donation and whether the topic had been discussed at home.

Methods

The participants were children in The Netherlands aged 12 through 15 years. The lower limit of 12 years was chosen because, according to Kohlberg[4] and Ondrusek,[5] from this age onwards children in general can be cognitively and emotionally capable of providing assent. Moreover, in the everyday routine of hospitals in The Netherlands, assent is common practice from 12 years onwards, since the law requires this. The upper limit of 15 years was used because in The Netherlands, from 16 years onwards the principle of informed consent is practiced; here we will focus on assent. At the time of the survey, the total population in The Netherlands of the children aged 12–15 years was 803 146.[9]

The children were recruited from an online children's panel organized and supervised by Dutch national public television's children's news program. The aim of the panel is to gain insight into opinions children have about social issues. Every child, aged 8–15 years that has the consent of its parents can enrol for the panel. Children were recruited through children's television and children's magazines and were accepted depending on demographic variables; age, sex, spatial distribution, type of school and class, family composition, type of housing and religion, so as to realize adequate representation of the Dutch child population. All children in the panel were regularly invited by e-mail to participate in specific surveys. For this survey all children aged 12–15 years old in the panel ($N = 5321$) were invited. The survey was open online for 3 days and 2016 children completed the entire questionnaire (response rate 38%): 1625 girls and 391 boys. The number of children per age group differed, the mean age was 13.3 years (SD = 1.02). To create a sample reflecting the normal age and gender distribution, the responses were weighted using RIM weighting. For each combination of age and gender, the findings were multiplied by a factor to ensure that each group had the same weight in the results. Table 1 shows the weighting factors.

Those children who replied to the e-mail invitation to take part in the online questionnaire were asked to answer the following questions (translated from the original questionnaire):

(i) Have you ever heard of organ donation or of becoming an organ donor? (Y/N)
(ii) Would you want to decide yourself about becoming a donor? Or is it OK with you if your parents decide and not you? (myself/parents/do not know)
(iii) Did you ever discuss becoming a donor at home? (never/once/more often)
(iv) Kids are not allowed to decide about donating their organs in case they die, but your parents are allowed to. Would you want to be a donor? (Y/N)
(v) Why would not you want to be a donor? (open)

The answers to the five questions were grouped according to age and sex, as outlined earlier. We then tested the representativeness of the respondents with regard to religion and type of housing (table 2). We also explored associations with socio-economic status (SES) and religious background of the family, and with the level of education of the middle school respondents themselves. We used the type of housing (flat/row house, duplex and villa) as a proxy of the SES of the children.

To test statistical relevance non-parametric analyses were performed (χ^2-test and Mann–Whitney test where appropriate). All statistical analyses were performed two-sided with α set at 0.05.

According to Dutch law a survey study like this one does not require approval by a medical ethical review board, which was confirmed for the present study by the medical ethical review board of the University Medical Center Groningen.

Results

Ninety-nine percent of the children had heard about organ donation and about the possibility of becoming a donor. The majority of the children (75%) preferred to decide for themselves about donation. Of the total number of children, 32% had never discussed organ donation at home, 25% reported having discussed the topic at home once and 43% reported that they had discussed this topic at home more than once. Sixty-six percent of the children were willing to donate.

Gender and age variation

Children who had heard of organ donation were significantly older than children who had not heard of organ donation (Mann–Whitney U-test

Table 1 Weighting factors (RIM) for each combination of age and gender

N = 2016	12 year old	13 year old	14 year old	15 year old
Girls (*N*)	419	517	445	244
Weighting factor	0.60	0.49	0.57	1.03
Boys (*N*)	122	132	84	53
Weighting factor	2.07	1.91	3.00	4.75

Table 2 Socio-economic status and (family) religion of the respondents (weighted) and of the general population in The Netherlands

The total population 12–15 years old: 803 146	Respondents (%) *N* = 2016	The Netherlands (%) General population	χ^2-test, *P*-value
SES based on type of housing			0.223
Upper (villa)	21	25	
Middle (duplex)	51	50	
Lower (flat/row house)	5	25	
Other/no reply	23	–	
Religion			0.241
Roman Catholic	17	29	
Dutch Protestant	16	19	
Islamic	2	5	
Other	6	5	
Non-religious	51	42	
Unknown/no reply	8	–	

Table 3 Children's answers (percentages) according to sex and age

N = 2016	Weighted for gender and age				Percentage of each age group, weighted for gender				
	Percentage of all respondents	Percentage of girls	Percentage of boys	Gender difference	12 year old	13 year old	14 year old	15 year old	Age difference
		N = 1625	*N* = 391	*P*-value (χ^2-tests)	*N* = 541	*N* = 649	*N* = 529	*N* = 297	*P*-value (Mann–Whitney or χ^2)
Have you heard of organ donation?				0.846					(*Z*) $P < 0.001$
Yes	99	99	99		97	98	99	100	
No	1	1	1		3	2	1	0	
Who should decide?				0.002					
Myself (a)	75	73	76		71	72	76	79	a–b: (*Z*) $P = 0.520$
Parents (b)	13	11	14		10	14	13	13	a–c: (*Z*) $P < 0.001$
Do not know (c)	13	16	10		19	14	11	8	b–c: (*Z*) $P < 0.001$
Have you discussed donation at home?									
Never	32	29	36	<0.001	32	33	33	33	(χ^2) $P < 0.776$
Once	25	23	26		23	27	25	24	
More often	43	48	38		46	41	43	43	
Would you like to become a donor?				0.008					(*Z*) $P < 0.001$
Yes	66	69	64		62	66	65	72	
No	34	31	36		38	36	35	28	

$Z = -4.21$, $P < 0.001$). Whether or not children had heard of organ donation did not differ between boys and girls (χ^2, $P = 0.846$). Table 3 presents the children's responses for the entire study population, with girls and boys separately, and for each age.

Children who wanted to decide for themselves did not differ in age from children who preferred to leave the decision up to their parents (Mann–Whitney U-test $Z = -0.643$, $P = 0.520$). Children who wanted to decide for themselves and children who wanted their parents to decide for them, however were older than those who answered 'I do'nt know' ($Z = -5.94$, $P < 0.001$ and. $Z = -5.14$, $P < 0.001$). Girls reported more often than boys that they did not know who should decide (χ^2, $P = 0.002$).

Girls discussed donation more often than boys (χ^2, $P < 0.001$). We found no differences between the age groups (χ^2, $P < 0.776$). Of the children who were willing to donate, 49% had discussed organ donation at home. This was significantly higher than in children who were not willing to donate (31%, χ^2, $P < 0.001$).

Girls were more willing to donate than boys (χ^2, $P = 0.008$). Moreover, children who were willing to donate were older than those who were not (Mann–Whitney U-test, $P < 0.001$).

Thirty-four percent of the children were not willing to donate. The most frequently reported arguments against donation were: 'I do'nt want it because it would make my body incomplete' (18% of all respondents); 'I think it's a scary idea' (5%); 'I do'nt want someone else walking around with my organs' (3%); 'I am afraid that they will do it when I am still alive' (1%); 'It is impossible because of my religion' (1%); other reasons (5%).

Socio-cultural variation

In order to place our results in a societal perspective, we conducted additional analyses based on three demographic variables: the SES and religious background of the family, and the level of education of the middle school respondents themselves.

We found a positive association for the SES with the child's familiarity with the topic (χ^2, $P = 0.002$) and with the number of times that organ donation had been discussed at home (χ^2, $P = 0.003$).

In the present sample, children with a mainstream religious affiliation (Roman Catholic and Protestant) and non-religious children reported being familiar with the topic more often than children with an Islamic background (χ^2, $P < 0.001$). Furthermore, non-religious and Roman Catholic children had discussed organ donation at home more often (χ^2, $P < 0.001$), and were more willing to donate (χ^2, $P < 0.001$). The religious background of the children was not found to be associated with their opinion on who should decide on organ donation (χ^2, $P = 0.347$).

Thirty-eight percent of the children were still in primary school and 62% had entered middle school (including junior high school). Thirty-one percent of all responding children had entered junior high school. The educational level of the middle school children was positively associated with familiarity with the topic (χ^2, $P = 0.010$), with independent decision-making (χ^2, $P = 0.001$), and with willingness to donate (χ^2, $P < 0.001$). We found no association between educational level and family discussions (χ^2, $P = 0.409$).

Discussion

In this study, we investigated the opinions and the capability to think about organ donation of children in The Netherlands in the age range of 12 through 15 years.

Before putting the results in perspective, we would like to emphasize that this study was set up as a survey, a first step towards empirical evidence. The results therefore can only be seen as indicative; further research is needed to replicate and test our findings.

We found that 66% would be willing to be a donor which is comparable to the 57% of adults who would in the Dutch Donor register.[10] The reasons why children were not willing to donate seemed comparable with the reasons given by adults that we encounter in our practice. Overall, children of 12 years and older seemed to be willing to think and decide about donation.

In surveys, the type of housing is sometimes used as a proxy for SES.[11] We also used this proxy and found that the associations between the children's responses and their SES resembled those previously observed in adolescent and adult populations. Research in adults shows that people with a high SES are better informed about health-care issues than people with a low SES.[12] Several studies have demonstrated that a favourable attitude toward organ donation is associated with the level of education.[12–14] Furthermore, empirical studies have demonstrated that attitudes towards organ donation differ among religions.[12,15] The

associations we found with these socio-demographical variables were supported by the observations in adults and adolescents. Finally, in our survey, girls appeared more positive about donation and discussed the topic more often. This is in agreement with the observation that girls are more aware of social and care issues than boys.[16] Although the present study was not designed as a cross-validation experiment, the findings are in line with associations between attitudes towards organ donation and socio-cultural and socio-economic variables as observed in adolescents and adults.

It is important to keep in mind why we undertook this study. Physicians are confronted with parents who are struggling with their wish to take their child's point of view on donation into account. Although it may sound logical to transpose to the parents the child's right of posthumous assent, this shift in perspective raises questions about at least three important preconditions closely connected to the concept of assent: maturity of the child, health literacy of the child, and accessibility to the opinion of the child.

When discussing maturity and health literacy, we use Kohlberg's work as a reference.[4] His theory states that moral reasoning, the basis for ethical behaviour, has a number of developmental stages. The level of moral reasoning which is typical for adolescents and adults is characterized by the ability to judge the morality of actions by comparing them to society's views and expectations, especially in terms of right and wrong. Empirical evidence shows that from the age of 9 years, children are cognitively and emotionally capable of providing assent under normal conditions.[5] The findings in our study do not lead to suggestions that this is any different for donation. Whether children have the necessary information to be able to meet the demands in terms of health literacy remains an unanswered question. Given the overlap with maturity, we focused on health literacy in terms of obtaining and understanding the basic health information and services needed to make appropriate decisions about donation.

Although we did not test the children's health literacy specifically with regard to organ donation, the reasons mentioned by the children refusing donation fit with an understanding of the concept which is similar to that of adolescents and adults. One should note, however, that we did not check for this in children who mentioned they were willing to be organ donors. Hence there is always the possibility that health literacy requirements were particularly met in those children who would refuse organ donation.

The other prerequisite is that parents should have access to their child's opinion in order to be able to take it into account. It is remarkable that 43% of the children responded that they had discussed organ donation at home more than once. This percentage, however, does not fit with our own clinical experience, which is that parents often have no idea what their child's wishes would be in such a situation. Although we did not ask about the content of these home discussions, it is likely that these conversations were experienced differently by parents and children. According to Waldrop,[8] conversations about these issues may be difficult to handle; they tend to generate so much anxiety and discomfort that parents often avoid these conversations. Waldrop further suggests normalizing family discussions about end-of-life choices by discussing thoughts and feelings about donation in a non-crisis situation. Others[2,17] point out that, in addition to family discussions, educational programmes about organ donation at school may support children in discussing the topic at home and in developing their own opinion. The present findings indicate that these children between 12 and 15 years are willing to participate in the discussions, and are cognitively and emotionally capable of doing so.

We emphasize that our study is only a first step towards empirical evidence about how assent relates to this subject. One might argue that the prerequisite of access to a computer and the internet in order to participate in this study may have led to a bias in recruitment of the participants. Indeed, in many countries access to the internet is limited. However, in The Netherlands almost 96% of households are connected to the internet and the use of restricting programs (such as Internet Nanny) is very limited. Hence, it is unlikely that use of the internet by itself has resulted in a bias in the selection of the population. Over-representation of respondents who are more aware of social issues and society at large may have occurred, as in any survey on this topic, and may be reflected by the higher response from girls compared with boys and by the relatively high numbers of children that had entered junior high school. In addition, we do not know the reasons for not responding. This weakness could be covered in future in-depth studies. Whether the present findings can be extrapolated to other countries also needs to be investigated in future studies. However, as stated above, our results are in line with previous findings for adolescents and adults.

The results of this survey indicate that these children at 12 through 15 years of age are capable and willing to think about the topic of organ donation. However, if we want to meet the conditions for assent, posthumous or otherwise, more empirical research is needed on how the concepts of maturity and health literacy relate to assent in more extreme situations such as organ donation. Also, more knowledge is required about how donation as a topic is discussed in families. From a more fundamental theoretical point of view, developmental psychology studies should address questions such as 'at what age' and 'under which conditions' these family discussions could and/or should take place. From a legal point of view, it would be interesting to study questions regarding whether and how the opinions of the child, as established in family discussions, should be recorded and under what conditions. Thirdly, in order to be able to help parents cope with the dilemma of whether or not to take into account their child's opinion on donation, medical staff should address the issue of posthumous assent in a very cautious and communicatively delicate way. If policymakers take the issue of posthumous assent seriously, thought should be given about how to raise awareness and how to enable parents and children to develop some sort of health literacy concerning the concept of organ donation. Finally, children and their parents should be given adequate opportunities to receive appropriate information, suited to their psychological and moral developmental status.

Acknowledgements

The authors thank the *Jeugdjournaal*—Dutch public television's children's news program—for providing the opportunity to conduct this research, and No Ties for their participation in the data assessment and their willingness to share their data for research purposes.

Conflicts of interest: None declared.

Key points

- Seventy-five percent of children aged 12–15 years preferred to make their own decisions about donation.
- Overall, children of 12 years and older seemed to be willing to think and decide about donation.
- Children need appropriate information about organ donation.
- For health policy: awareness of parents and their children of organ donation should be developed.

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European Journal of Public Health, Vol. 22, No. 4, 533–538

doi:10.1093/eurpub/ckr089 Advance Access published on 11 July 2011

Explanations for social inequalities in preterm delivery in the prospective Lifeways cohort in the Republic of Ireland

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Background: Social inequalities in pregnancy outcomes have been extensively described but studies that explain these inequalities comprehensively are lacking. This analysis evaluated the contribution of material, psychosocial, behavioural, nutritional and obstetrical factors in explaining social inequalities in preterm delivery. **Methods:** The data were based on a prospective cohort of 1109 Irish pregnant women. Preterm delivery was obtained from clinical hospital records. Socio-economic status was measured using educational level. The contribution of the above factors in explaining the association between educational level and preterm delivery was examined using Cox models. **Results**: Educational level was found to be a significant predictive factor of preterm delivery; women with low educational level were more likely to have a preterm delivery [hazard ratio (HR) = 2.14, 95% confidence interval (95% CI): 1.04–4.38)] after adjustment for age and parity. Rented and crowded home, smoking, alcohol consumption and intake of saturated fatty acids displayed educational differences and were predictive of preterm delivery. Material factors (rented and crowded home) reduced the HR of preterm delivery for low compared with highest educated women by 33%. The additional independent contribution of behavioural factors (smoking and alcohol consumption) was 5% and of saturated fatty acids intake was 4%. All these factors combined reduced the HR of preterm delivery for low educated women by 42% (HR = 1.66, 95% CI: 0.76–3.63). **Conclusion**: This study underlines the importance of material, behavioural and nutritional factors in explaining social inequalities in preterm delivery. These findings have cross-sectoral public policy implications.

Introduction

Pregnancy outcomes such as low birthweight and preterm delivery are considered to be major risk factors for subsequent morbidity and mortality of newborns. Low birthweight may be related to a variety of causes including premature birth, intrauterine growth retardation or a combination of both. These outcomes may be linked to different aetiological mechanisms and risk factors may differ according to the outcome studied. Thus, separate analyses for each outcome seem important when considering social inequalities in pregnancy outcomes.[1,2]

Social differences have been reported repeatedly for preterm delivery including very preterm delivery,[3–7] lower social groups being at higher risk for this outcome. These inequalities in early life may predict health in later life and may explain, at least in part, the accumulation and addition of risk factors over time and across generations.[8,9] Consequently, understanding the mechanisms underpinning these inequalities is a major public health issue.

Yet, comprehensive studies exploring precisely the underlying mechanisms linking socio-economic status (SES) to preterm delivery are still lacking. To our knowledge, only a few studies have attempted to explain social inequalities for this outcome but they were not able to cover the full range of potential explanatory factors and focused on a very limited number of factors such as smoking or body mass index (BMI).[4,5,7,10] Kramer[1] was one of first authors to summarize the range